

In recent years, the Spina Bifida community has seen a growing incidence of sudden death in its over 25 population. There is speculation this sudden loss of life has something to do with the central nervous system, but the cause or causes remain unknown. As such, we must explore and understand this sudden death phenomenon so we can reverse this troubling trend. Moreover, we must support—and expand investment in—research to address other issues related to Spina Bifida and associated secondary and co-morbid conditions, such as hydrocephalus, latex allergy, neurogenic bladder and bowel problems, developmental delay, and impaired executive functioning.

The CDC's National Spina Bifida Program is the sole federal program tasked with improving the care and outcomes for people with Spina Bifida. In 2008, the Spina Bifida Program created a National Spina Bifida Patient Registry (NSBPR) to collect the scientific data needed to evaluate existing medical services for Spina Bifida patients, and to provide clinicians, researchers, patients, and families a "window" into what care models are effective and what treatments are not making a measurable difference. Building on this in 2014, the Spina Bifida Program funded the development of a Spina Bifida Collaborative Care Network (SBCCN) to identify and disseminate "best practices" for the care of people with Spina Bifida at all ages. These programs continue to improve quality-of-life and outcomes for people with this birth defect, but their full potential has been constrained due to flat federal funding over the last six years. Additional funding could expand the number of clinics participating in the registry and increase the amount of information reported, which will provide further insights into how to continue improving care and outcomes for people with Spina Bifida.

People with Spina Bifida deserve no less than the rest of us as we age. During a lifetime, someone with Spina Bifida will face at least a \$1,000,000 in medical expenses, including multiple surgeries, and most can expect to spend much of their lives in a wheel-

chair or walking with braces. We must ensure that adults with Spina Bifida can receive evidence-based medical care tailored for their condition and receive that care in age-appropriate, non-emergency settings. I call upon my Congressional colleagues to prioritize increased funding for the CDC Spina Bifida Program to ensure that it will be poised to best guide the health care community in optimal treatment options for people living with Spina Bifida.

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IN RECOGNITION OF THE LIFE  
AND MEMORY OF MR. PAUL  
WRABEC

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**HON. EMANUEL CLEAVER**

OF MISSOURI

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, October 26, 2021*

Mr. CLEAVER. Madam Speaker, I rise today with a heavy heart to celebrate the life and legacy of a dear friend, an ambitious leader, and a dedicated public servant: Paul Wrabec. Paul, who passed away on October 20th, never faltered from advocating for the causes he was deeply passionate about, and his advocacy undoubtedly made Jackson County a better place to call home. As a beloved and active member of the Greater Kansas City community, he created change and inspired future generations of policy makers to lead with a sense of conviction. Paul will be missed dearly, and his life is well worth remembering.

A lifelong resident of Sugar Creek, Missouri, Paul comes from a proud Croatian and Slavic family that immigrated to the United States in the early 1900s. Growing up in this thriving immigrant community, Paul was taught the values of equality, union rights, and environmental stewardship. Throughout his life, Paul remained committed to those values as he led a fulfilling career as a civil servant.

A graduate of St. Mary High School and Rockhurst University, Wrabec retired from environmental remediation work in 2005. Oper-

ating the Kansas City, Sugar Creek, and Independence License offices with his son, Cyril, Paul ensured that disabled and elderly members of the community had access to much needed services. But his impact as an empathetic community member didn't stop there.

Paul also served on the Sugar Creek Board of Aldermen, and then was first elected to the Jackson County Democratic Party committee in 1978 and was its longest-serving chairperson in nearly 100 years. He was known throughout Jackson County for being able to "run circles" around others in fundraising and for constantly raising the bar for successful local campaigns. Always emphasizing the importance of voting, Paul worked tirelessly to rally communities throughout Independence and Sugar Creek ahead of critical elections.

While Paul certainly wore his political beliefs on his sleeve as a loyal Democrat, he was a steadfast believer in building relationships with those across the aisle. Indeed, he found ways to make peace with people from all walks of life, and his gentle demeanor and contagious smile always made him a joy to be around. There is no doubt that he established a connection with every individual he came across.

Looking beyond his extraordinary work as a public official, Paul was a heartfelt family man who enjoyed hunting and fishing at the Lake of the Ozarks with his family. Making time for his loved ones was always his first priority. Paul's storytelling of family history and generous nature will be missed, but all those who have met him will still have felt his impact for the rest of their lives.

Many still remember times when Paul picked up hitchhikers, gave money to the homeless, and happily lent a helping hand to anyone needing anything.

Madam Speaker, please join me in remembering the inspiring, impactful life of Paul Wrabec. Please also join me in offering condolences to his family and all those mourning his loss. Let us seek to emulate his example in the work we do here by preserving Paul's story of public service and human empathy.